

340 Enjoying learning – CF school can be fun!

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Introduction: Cystic Fibrosis (CF) is a life shortening genetic disease. Life expectancy has increased as a result of more complex, demanding daily treatments. Including prolonged airway clearance sessions, inhalations, oral antibiotics, pancreatic enzymes and high caloric diet. There is a strong correlation between knowledge about the disease, reduction of anxiety and improved adherence to treatment.

Goal: To assess an experiential learning program about CF treatment provided within a supportive framework to children with CF aged 6 to 12 years and their families.

Method: Four 3-hour interactive workshops were provided for the children, related to infection, airway clearance, nutrition and emotional aspects of CF respectively. The sessions were run by the social worker and nurse in Arabic and Hebrew. In parallel, the psychologist led a parental support group accompanied by members of the multidisciplinary team according to the topic. At the end of the program a satisfaction survey was completed by all the participants.

Results: Participants included: 9 children with CF (4 girls, 5 boys), average 8.5 years, 9 siblings/friends and 12 parents (7 mothers, 5 fathers). The average satisfaction score out of 4 was 3.8 for the children and 3.2 for the parents. The meetings enabled attainment of knowledge (less for parents), sharing and legitimization of feelings associated with the CF illness.

Conclusion: Providing knowledge about CF within a supportive and interactive framework to children with CF and their families had high satisfaction levels for both parents and children. Parents have a greater need for emotional and social support than information about the illness.

342 Adaptation to cystic fibrosis related diabetes – "I'll get to that page when I'm ready"

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Background: Cystic fibrosis related diabetes (CFRD) is the most common comorbidity in patients with cystic fibrosis (CF). Despite this, there is little research on the psychological impact on patients. This qualitative study explored the experiences of patients with CFRD, and how services might best support them.

Method: Patients diagnosed with CFRD after January 2007 (n=11) were interviewed about their perceptions of the diagnosis, ways of coping and support received. Transcripts were analysed using grounded theory through a process of open coding and grouping into major themes.

Results: 4 key themes emerged; **1. Beliefs at diagnosis:** all participants mentioned a sense of inevitability and many commented on emotional impact. Several held misconceptions about CFRD. **2. Knowledge:** this was limited and patients expressed very different information needs, including preferences for different timing and mode of information. **3. Coping style:** this was linked to knowledge and caused frequent conflict between what worked well for the individual but not for overall management of CFRD. **4. Identity:** patient's varied in how CFRD had changed their perception of themselves; a major issue was controlling the degree of visibility of CFRD.

Discussion and Conclusion: The study has given a clear basis to inform further service provision, suggesting a focus on the personalised knowledge, practical management and information needs of patients with CFRD.

341 Implementation and evaluation of a therapeutic educational multidisciplinary program within the paediatric clinic for cystic fibrosis

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Background: Therapeutic education (TE) has the purpose to improve understanding of the disease, its complications and needs for treatment.

Objective: implementation and evaluation of TE in a pediatric CF consultation. Primary endpoint: FEV1% & FEF25–75%. Secondary endpoint: Evaluation of disease knowledge and quality of life (CFQ[®]).

Method: Open interventional study in patient ≥ 6 years. Patients were followed on their regular 3-month basis over 2 years. Interventional education by CF physician and nurse took place at each visit with assessment once yearly. At visit 1, a contract defining the content of the educational program, according to patient, family and CF team expectations was discussed. We used tools created and validated by the GETHEN. At the end of the study we tested the knowledge about nutritional aspects of the disease in the study group and in the control group.

Results: Out of 32 patients from 6 to 16 years, 17 accepted the study; the 15 who denied were used as control group. FEV1 increased 5.3 % in the study group versus a decrease of 3.6% in the control group (p < 0.02), and FEF25–75% increased 8.3% versus decrease of 0.5% (p < 0.5). In the study group, scores of knowledge obtained were between 22 and 28 (maximal score), in comparison to 15 and 27 in the control group. For CFQ[®] data were not conclusive.

Conclusion: Using TE, there is a clear trend to improve lung functions (+5.3% vs -3.6% over 2 years time) as well as disease-knowledge, despite the small number of patients and the fact of a certain bias to take as control group patients who refused participation. In motivated patients and families, TE could be an important strategy to stabilize lung function.

343 FEV1 % predicted – patients' understanding, perception and reality

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Background: In our adult tertiary care centre, we routinely quote patients' spirometry as absolute values, rather than as percent predicted. This study was performed to explore patients' understanding of spirometry, what FEV1 means, and how their lung function relates to predicted values.

Method: Face to face questionnaires were completed with a random sample of 25 patients attending outpatient clinics. Subjects were asked to define FEV1 and FEV1 % predicted. Patients unfamiliar with these terms were provided with a written definition. All participants were asked to estimate their FEV1 % predicted, which was then compared to actual values.

Results: Of the 25 participants: 15 (60%) were unable to accurately define FEV1. 16 patients (64%) had never encountered the term FEV1 % predicted, 5 (20%) had heard the term but did not understand it, and 4 (16%) defined it correctly. 8 patients (32%) had been previously informed of their FEV1 % predicted; this group had the smallest mismatch between their perceived FEV1 % predicted and actual value. 5 (20%) underestimated their values and 20 (80%) overestimated. Those with lower values had a better understanding of their health and there were smaller gaps between perceived and actual values. Of the 25 participants 22 wished to know their actual values and were referred to a consultant for further discussion.

Conclusion: There is significant discrepancy between perceived and calculated FEV1 % predicted, and a tendency for patients to overestimate their lung health. Improved information will hopefully lead to improved understanding, allowing more informed lifestyle/treatment choices.